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ABSTRACT

This paper examines procedures utilized in five social systems in affixing the label of disability on a sample of the developmentally disabled in three counties located in a Southern state. The social systems are: medical clinics, public schools, governmental and semigovernmental agencies, civic organizations, and families and neighbors. The objective is to compare the developmentally disabled persons nominated by these social systems in terms of degree of help sought from others, and dependence on public and private welfare agencies. Data were gathered from 364 disabled persons whose disabilities were mental retardation, cerebral palsy, and/or epilepsy. Statistical analyses revealed that characteristics of the disabled varied from one social system to another. Furthermore, the labeling process itself was mainly "reputational" in certain social systems and more "technical" in others. This research project, although only a beginning, speaks to the mislabeling that can occur when persons vary from the "norm". (Author)

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LABELING THE DEVELOPMENTALLY DISABLED:

A SOCIAL-SYSTEM APPROACH¹

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Researchers dealing with social aspects of physical disabilities have long recognized the influence of cultural values and role expectations in affixing the disability label on the client. Of the three types of developmental disabilities--mental retardation, cerebral palsy, and epilepsy--mental retardation occupied the center of attention in early studies. O. E. Lewis (1929; 1933) was probably the first to recognize the "subcultural" types of mental deficiency and investigate the influence by the complexity of the social system in their development. In the 1940's researchers like McCulloch (1947) and Klapp (1949) were influential in bringing to light the contention that mental retardation is a function of levels of tolerance and degrees of deviation from patterns of expectations. During the 1950's it was Kanner, a clinician by training, who identified one type of mental retardation as consisting of "individuals whose limitations are definitely related to the standard of the particular culture which surrounds them" (Kanner, 1957:71).

Social-system analysis of developmental disabilities gathered a great deal of momentum in the 1960's and early 1970's due to contributions of a large number of researchers in all three types of disabilities. Social circumstances fostering or directly influencing the likelihood of occurrence of epilepsy and/or cerebral palsy were recognized by Alder (1961), Mitchell (1962), Ingram (1964), Klapper and Birch (1966), Bowley (1969), and Alter and Hauser (1972). But it was the field of mental retardation

with its growing number of sociologically minded researchers that spearheaded a movement toward emphasizing social-system analysis of physical disabilities. The list included Dexter (1960), Heber (1961), Mercer (1965; 1970; 1971; 1972), Perry (1966), Edgerton (1967), and Mercer et al (1964).

Social-system analysis of labeling the developmentally disabled entered a new stage of maturity with Mercer's book, Labeling the Mentally Retarded (1973). In this volume Mercer presents a comprehensive social-system epidemiology of mental retardation in Riverside, California. She delves into, among other facets, achievement of retardation, effects of labeling the client with disability by the various formal and informal systems of the community, and analysis of sociodemographic characteristics of retardates.

This paper extends Mercer's analysis to five social systems in three counties located in a Southern state. The social systems are medical clinics, public schools, governmental and semigovernmental agencies, civic organizations, and families and neighbors. Specifically, this research investigates patterns of labeling followed by these five social systems through analysis of nominees of each social system in terms of degrees of disability, help sought from others, and dependence on public and private welfare agencies. The general proposition guiding the research is that nominees of the different social systems show significant variations in areas of behavior mentioned above.

THEORETICAL RATIONALE

Building on Mercer's (1973) work, this study assumes that developmental disabilities, although primarily medical-pathological phenomena, are outcomes of social definitions.² Disabilities, as perceived by persons occupying positions in social systems who nominate disabled individuals, are societal reactions to performances of tasks linked to role-sets.³ These role-sets are clusters of behavior; they are parts played by occupants of positions in groups.

Role performances of developmentally disabled nominees are deviant in that they vary sufficiently from expectations of members of social systems to be selected for the purpose of nomination. The degree of perception of disability is a function of the interaction of both "causes" of deviation: role performance by the disabled nominee and the system's expectations (Mercer, 1973:21-22; Scheff, 1966; Kitsuse, 1962). A nominee may be defined

²The debate between proponents of labeling theory and those who advocate psychiatric perspective is much involved and expansive. This paper does not attempt a defense of labeling theory nor does it attempt to discredit psychological processes leading to emergence of developmental disabilities. As Scheff (1975) ably states, it is certainly defensible to test "purely models of behavior" even though such models are rooted in physiological grounds. Moreover, testing one model of reality does not necessarily imply denial of validity of others. Scheff reminds us that when Durkheim wrote Suicide he "did not say that psychological or other processes played no part in suicide, but only that the social processes involved could be studied independently in their own right (Scheff, 1975:256). For recent literature dealing with the issue see Gove and Howell (1974), Scheff (1974), Harris (1975), Chauncey (1975), and Gove (1975).

³Names of disabled persons used as subjects in this research were nominated by residents of the three counties covered in this study. These residents then were "assigned" to one of the five social systems suggested in this paper depending on the "dominant" position they occupy in their respective communities. Thus, for instance, if the name of a disabled person was suggested by a physician or nurse, the disability is defined as affixed by the medical-clinic system. More details about the nomination process are given in the section on Methods.

by one social system as a disabled person when other social systems may not do so. Put in another way, social systems may use different criteria with different degrees of emphasis on these criteria in their nomination process.

Following Mercer, these criteria stem from consideration by the person affixing the disability label of five aspects of the normative structure of the system. They are: (1) The content of the norms, i.e., the specific behavior which fulfills the system norms; (2) the focus of the norm, i.e., the specific aspect of behavior upon which the evaluation process is based; (3) level of expectation, or quality of performance; (4) degree of formalization of the norms; and (5) degree of tolerance of deviation from the norm (Mercer 1973:23-25).

(Figure 1 about here)

These sets of theoretical relations lead to the following hypotheses:

- H₁: Affixing the disability label varies from one social system to another.
- H₂ The greater the number of social systems nominating a person for a disability, the less his ability to perform routine daily tasks.
- H₃ The greater the number of social systems nominating a person for a disability, the more help sought from outside.

METHODS

Data for the present analysis were gathered from representative samples of parents, guardians and/or close relatives of 364 developmentally disabled persons in three small counties in a Southern state. Two counties "represented" the polar distribution of racial groups of the state and the third has a ration of black-to-white population close to that of the state. All three counties are predominantly rural.

The process of identifying the subjects consisted of two stages:

- (1) Identifying community sources which were knowledgeable enough to nominate as many known developmentally disabled persons as possible and to provide some information regarding their places of residence. These sources included medical facilities, public schools, welfare agencies, local governmental and semigovernmental agencies, local community leaders and businessmen, neighborhood clubs, and families. (2) Drawing representative samples from pools of nominees provided by these sources after considering such factors as size of the county, type of disability, and degree of medical and/or psychological verification of the disability.⁴

The questionnaire used in the interviews included a relatively large number of items designed to measure a variety of variables other than those used in this paper. The four basic variables were operationalized as follows:

A. Labeling by social systems. This variable was measured by asking directly that the person making the nomination describe the disability, specify its extent, and recall any behavior the nominee engaged in. When the nomination was made by physicians, public health nurses, special-education teachers and the like, registers of agencies with which the informant was associated were used as sources for operationalization.

B. Strength of label. An assumption was made that the greater the number of social systems nominating a person for a disability, the stronger the label. Simple addition of the total number of social systems nominating

⁴It must be noted that data used in this paper were originally gathered for a state governmental agency with the explicit objective of providing it with results of a survey of needs and socioeconomic conditions of the disabled population of the state. Plans for testing hypotheses related to labeling theory were advanced after the data were collected.

a person was used to operationalize the strength of the label. No attempt was made to weigh the "quality" of the label given by each social system.

C. Degree of help sought from outside. The questionnaire included a number of items which are employed in this paper to operationalize this variable. They are: seeking help from immediate groups, seeking help from welfare agencies, seeking monetary help from others, seeking help because of feeling sad, and seeking help because of stigma.

D. Ability to perform routine daily tasks. This variable was measured by seven items dealing with walking, dressing, feeding oneself, reading, conversing, attending school (if the disabled was of school age), and holding a job.

ANALYSIS

Correlations Among the Dependent Variables

Product-moment correlations for twelve variables measuring the two dependent variables of the second and third hypotheses are shown in Table 1. The items are divided into two groups, with the first seven measuring the ability to perform daily tasks and the last five dealing with patterns of help sought from outside.

(Table 1 about here)

A number of observations relevant to the theory adopted in this paper can be made. As the table shows, the values of correlation among the first three items are very high (.85, .89 and .91). This should not be surprising since each of these items deals with a facet of the daily motor activities the disabled person engages in. Also, not surprising are the not-significant positive correlations between the three motor items and the fourth item (reading) which is the first of three measuring

the cognitive ability of the disabled. Correlation values climb to a significant level for the variable dealing with the ability to converse, reaching a rather high level when related to reading ability ($r = .71$).

The item dealing with attending school must be looked upon from two different angles. The first, focusing on the relationship with walking, dressing, and feeding, shows a series of negative values (-09, -15, -07). Although none of these correlations is significant, they are in the predicted direction, indicating that attending school is not necessarily affected by "pure" motor abilities of the disabled person. The second angle provides rather strong positive correlations (.71, .52) indicating that reading and conversing are requisite conditions for attending school.

The final item measuring the functional performance of the disabled--holding a job--shows an almost opposite pattern of association to the preceding item. While it correlates strongly with the motor activities of the disabled (.85, .85, .86), it fails to show any significant correlations with the more cognitive behavior (reading = .14, conversing = .09, attending school = .08). The apparent explanation is that the process of holding jobs among the adult disabled of the subjects of the study, who tend to be employed in manual occupations, was conditioned by a measure of dexterity and that the cognitive aspects were not significant for successful employment.

The five items measuring degrees of help sought from outside show a variety of patterns of association among themselves and with those dealing with functional performance. For instance, the item dealing with seeking help from immediate groups shows consistently not-significant negative correlations. Our theory predicted that these correlations would be significantly negative. On the other hand, seeking help from welfare agencies

(item number 9) shows a rather mixed pattern of correlation. While it leans toward positive association with some of the functional performance items, a totally unexpected result, it does show two negative correlations with attending school and holding a job (-.30, -.70). Furthermore it is consistent with our prediction that it positively correlates with seeking help from relatives ($r = .37$).

The next two items--seeking monetary help and seeking help because of feeling sad--are partially consonant with our prediction. Both of them lean toward negative association with performance of daily tasks although none of the relationships is significant. On the other hand, both show consistent positive correlation with other patterns of help-seeking behavior (.42, .61, .80, .81, respectively). The latter (seeking help because of feeling sad) correlates weakly with the former ($r = .30$).

The correlation values of the last item of the matrix perhaps fit better with the expected results than other items of help-seeking behavior. The negative associations with ability to perform daily tasks are divided equally between strong to moderate with the motor aspects (-.78, -.40, -.40) and weak with more cognitive patterns of behavior. On the other hand, the item shows significant positive associations with three of the four modes of help-seeking behavior included in the measure of the variable.

Results of Hypotheses Tests

Table 2 provides summary tests for H_1 .

(Table 2 about here)

The hypothesis argues that the five social systems--medical clinics, public schools, governmental agencies, civic organizations, and families and neighbors--

differ in their nomination patterns. Results shown in the table reveal that nominations by medical clinics and by families and neighbors were not influenced by either of the two clusters of items used in measuring the two behavioral variables (see Table 1). Specifically, the daily performance of the disabled and his help-seeking behavior were not a significant consideration in the nomination process by informants associated with clinical systems or the family and neighbors. This finding does not contradict Mercer's observation that "persons nominated most frequently by their acquaintances and neighbors would exemplify the characteristics most likely to influence their visibility as subnormals to persons in the community" (Mercer, 1973:86). On the other hand, if our remaining three social systems are taken as equivalent to Mercer's nonclinical organizations, then our finding stands in disagreement with Mercer's, which maintains that "persons nominated by clinical organizations" did not differ from "those nominated by nonclinical organizations" (Mercer, 1973:68).

Table 2 also shows that the remaining three social systems tend to follow a similar pattern in nominating disabled persons. Results of analysis of variance reported in the table indicate that the nominee's daily behavior and his help-seeking activities significantly affected the decisions of public school officials, government employees, and leaders of the community in nominating persons to the disability status.

Regression analysis for patterns of nomination followed by the five social systems tends to dilute the amount of confidence in the finding stated above except, perhaps, the case of public schools. As Table 2 reveals, only public schools show a moderate coefficient value ($R = .3955$). Even in this system, however, the amount of variance explained by the relationship is about 16 percent, a rather minor portion.

In Table 3 results of tests for H_2 and H_3 are shown. Focusing on

(Table 3 about here)

the former, the table indicates that frequency of nomination tends to affirm a specific pattern of behavior in both the motor and the cognitive facets of daily activities. (See discussion of the correlation matrix.) The same observation can be made regarding the third hypothesis. That is, there is a significant amount of interaction between frequency of nomination and degree of help sought by the disabled. (F - Ratio = 16.63, significant at the .001 level.) Here again regression analysis shows that in both hypotheses neither the values of coefficients ($R = .2689$ and $R = .2091$, respectively) nor the amount of variation explained by the relationships ($R^2 = .0723$ and $R^2 = .0437$, respectively) reached significant levels.

DISCUSSION AND CONCLUSIONS

The preceeding analysis points to a number of observations about the theoretical model posited earlier in the paper. First, the correlation matrix (Table 1) clearly reveals that a number of relationships between the items used to operationalize the two dependent variables, although statistically significant, did not constitute a pattern clear enough to produce systematic convergence with the independent variables. As a result, tests of association did not reach a significant level except in few cases.

Second, the sociocultural framework for analysis of developmental disabilities is not "mature" enough to take into account other variables affecting the phenomena. Mercer's push for a sociocultural pluralism that converges the clinical and the social systems together may be a solution to this problem (Mercer, 1973:255-272).

Third, closely related to the preceeding point is the question of adequacy of measurements used in this study. Neither the cognitive measure nor the items used to operationalize motor activities were broad enough to account for the diversity of the activities of the disabled.

Regarding the problem of accounting for variance, the obvious explanation must be related to the number of independent variables used in the hypotheses. Our theoretical model depicts a rather large number of such variables. However, the nature of the data severely limited the extent to which additional variables could be added to the test models.

Aside from these methodological limitations the labeling framework used in this paper must still be looked on as a viable guideline for further hypothesis testing. Tests of significance presented in Table 1 show the potential effectiveness of the model in predicting patterns of nomination in three social systems. Criteria used for nomination in these systems are probably of the "reputational" type (roughly equivalent to Mercer's situational retardation). (See Mercer, 1973:83-123.) Clinical systems, on the other hand, are more likely to label as retardate even the "intelligent" person if he happened to show a measure of physical disability due to the dominance of physical appearance in formation of perception of their members (Mercer, 1973:71). Taking these differences into consideration, one might suggest a tentative typology consisting of reputational labeling versus pathological labeling for future analysis of patterns of nomination of developmentally disabled persons.

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FIGURE 1

PARADIGM OF LABELLING THE DEVELOPMENTALLY DISABLED

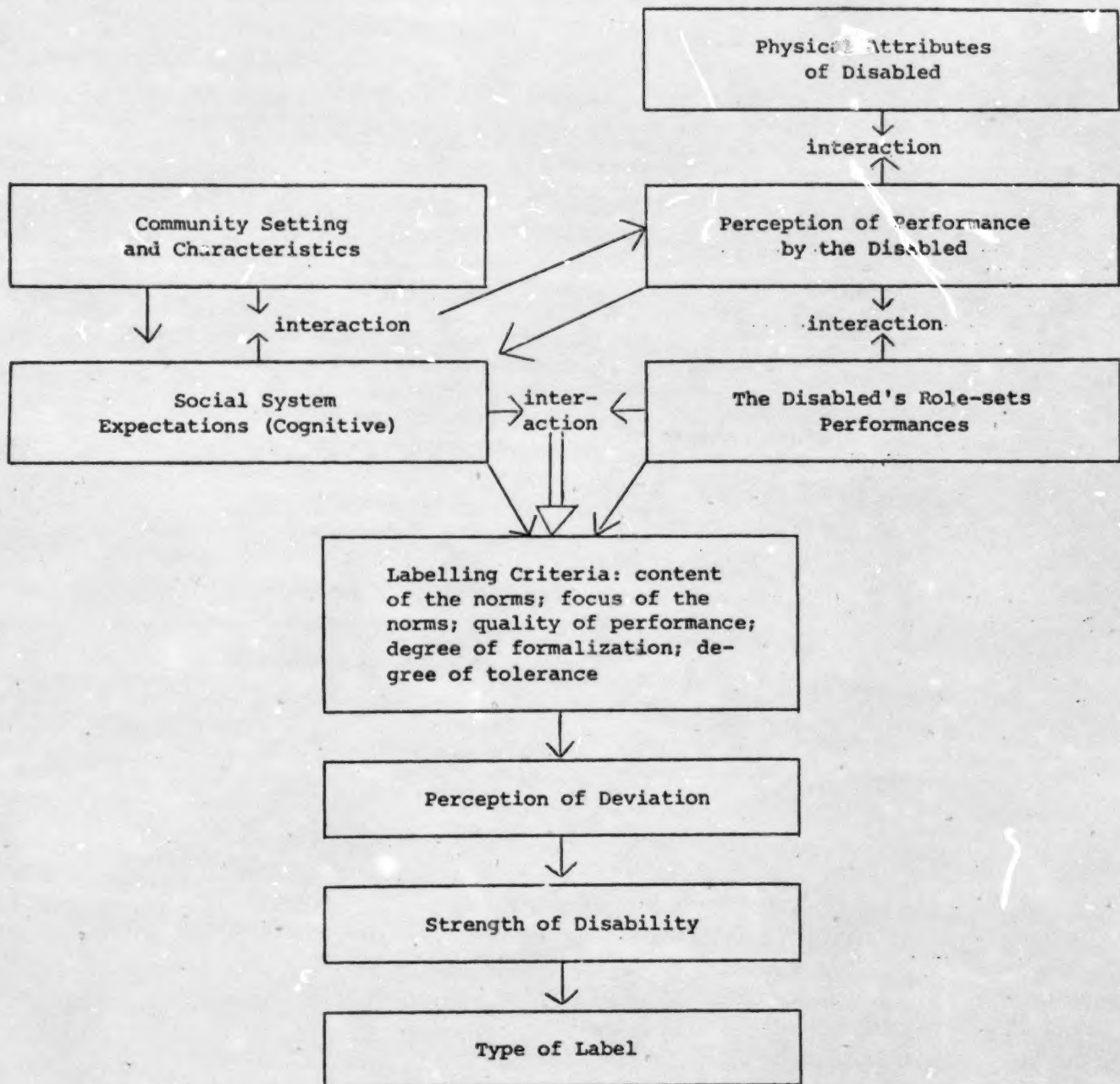


TABLE 1

PRODUCT-MOMENT CORRELATIONS OF ITEMS MEASURING DAILY FUNCTIONAL PERFORMANCE AND DEGREE
OF HELP SOUGHT FROM OUTSIDE*

Variable	1	2	3	4	5	Variable 6	7	8	9	10	11
1. Walking	-										
2. Dressing	85	-									
3. Feeding oneself	89	91	-								
4. Reading	12	04	10	-							
5. Conversing	36	32	35	71	-						
6. Attending school	-09	-15	-07	71	52	-					
7. Holding a job	85	85	86	14	09	08	-				
8. Seeking help from immediate groups	-12	-12	-10	-06	06	-16	-03	-			
9. Seeking help from welfare	15	15	18	-05	07	-30	-70	37	-		
10. Seeking monetary help	-05	-03	-02	-20	-10	00	-03	42	61	-	
11. Seeking help for feeling sad	-05	-02	-05	-09	-09	00	-20	80	81	30	-
12. Seeking help because of stigma	-78	-40	-40	-13	-06	-07	50	20	40	40	71

*Decimal points and plus signs omitted

TABLE 2

SUMMARY OF TESTS OF REGRESSION AND ANALYSIS OF VARIANCE FOR TYPE OF NOMINATING
SOCIAL SYSTEM AND DAILY PERFORMANCE AND HELP-SEEKING BEHAVIOR OF THE DEVELOP-
MENTALLY DISABLED

Type of Social System	Daily Performance			Help Seeking Behavior		
	R	R ²	F-Ratio	R	R ²	F-Ratio
		Items 1,2,3,4,5,6,7a			Items 8,9,10,11,12a	
Medical Clinics	.1852	.0343	1.807	.1074	.0115	.836
Public Schools	.3955	.1564	9.430***	.2254	.0508	3.832*
Govt. Agencies	.1888	.0356	1.879	.1956	.0383	2.849*
Civic Orgs.	.2791	.0779	4.296**	.1748	.0305	2.256*
Families and Neighbors	.1875	.0352	1.856	.1371	.0188	1.372

Items are discussed in the Methods section and Table 1.

*Significant at .05 level

**Significant at .003 level

***Significant at .001 level

TABLE 3

SUMMARY OF TESTS OF REGRESSION AND ANALYSIS OF VARIANCE FOR FREQUENCY OF
NOMINATION AND DAILY PERFORMANCE AND HELP-SEEKING BEHAVIOR OF THE DE-
VELOPMENTALLY DISABLED

Independent Measures	Daily Performance		Help Seeking Behavior	
	R	R ²	R	F-Ratio
Frequency of Nomination	.2689	.0723	.2091	.0437
		28.360*		16.636*

Items are discussed in the Methods section and Table 1

*Significant at .001 level